B.4 Examine MCH Program Capacity by Pyramid Levels

**DIRECT HEALTH CARE SERVICES AND ENABLING SERVICES ARE COMBINED**

**Wisconsin Medicaid**

Both federal and state tax dollars support Medicaid. For state fiscal year 1998, Medicaid expenditures were $2.52 billion. Of that amount, $905 million was contributed by the state and nearly $1.61 billion by the federal government. Medicaid is the second largest program in the state's budget, representing 9.3% of total state-funded expenditures. The program costs have increased over the years primarily due to expanded eligibility and rising health care cost.

Four major groups received medical services through Medicaid: the aged, the blind/disabled, the Healthy Start population, and recipients who qualified under the former Aid to Families with Dependent Children (AFDC) standards. Of the total Medicaid-eligible recipients, well over half were eligible through AFDC or Healthy Start, accounting for 19% of Medicaid expenditures. The aged/blind/disabled make up approximately 35% of the eligible population and account for 81% of the program expenditures.

/2003/ In the most recently completed biennium, 1999-2001, total Medicaid funding amounted to $1,968,154,500 state funding and $3,627,753,800 in federal funds, for a total of $5.6 billion. For BadgerCare, state funds contributed $68,087,000 and federal funds contributed $126,331,900. Program revenue, in the form of enrollee premiums, added $3,408,500, for a total BadgerCare expenditure in the biennium of $197.8 million. Overall, $5.8 billion was spent on Medicaid and BadgerCare in Wisconsin during the biennium. //2003//

/2004/ In the completed state fiscal year, 2001-2002, total Medicaid funding amounted to $1,325,160,415 in state funding and $2,278,940,713 in federal funds, for a total of $3.6 billion. For the BadgerCare Program alone, $43,888,990 was budgeted in state General Purpose Revenue, augmented by $86,884,200 in federal revenue. Program generated income, in the form of enrollee premiums, amounted to $2,994,400. With a small amount of additional revenue, the total amount of budgeted funding for the fiscal year equaled $134,096,000. However, the Legislature added an estimated $227,000 in additional revenue during the fiscal year to defray added costs. About $454,000 is expected to be added in 2002-03 for similar reasons. //2004//

***/2005/*** *The Wisconsin Medicaid budget, driven by continuing increased enrollments and increased costs of drugs and other services, continues to rise. In state fiscal 2002-03, the total all-funds budget for Medicaid and BadgerCare was $4.1 billion, a 13.9% increase over the previous state fiscal year. A critical current legislative issue was the need to address a Medicaid revenue shortfall of roughly $400 million.* ***//2005//***

**Medicaid Expansion**

Wisconsin was one of the first states to initiate managed care for the AFDC/Healthy Start Medicaid population by receiving a federal waiver in the early 1980s. The HMO program expanded statewide in 1996 and 1997 beyond the original five counties. Expansion for the AFDC/Healthy Start population into additional counties occurred systematically in three phrases staring in the eastern Wisconsin counties. By the end of 1997, over 290,000 Medicaid recipients had enrolled in 18 HMOs in 70 counties for at least a part of that year.

According to the 1997 Wisconsin Medicaid HMO Comparison Report: (data on health care delivered by HMOs enrolling Medicaid recipients) for most health care areas measured, health service utilization is quite stable relative to 1996 and HMO enrollees in Milwaukee County are largely satisfied with their care.

Relative to 1996, there were slight to moderate improvements in the utilization rate of:

- HealthCheck screens. Approximately 94% of eligibles were screened per eligible-year through HealthCheck services.
- Non-HealthCheck visits. These visits are an indication of the ease with which children receive routine and acute care. The availability of these visits helps establish a primary "medical home" for children enrolled in the AFDC/Healthy Start Medicaid population.
- Cesarean sections. C-Section rates continue to meet federal goals.
- Pap tests.
- MMR immunizations.
- Hospitalization for asthma. The development and implementation of care management for enrollees with asthma resulting from inter-HMO cooperative efforts, will likely result in further reduction of hospitalizations for this population.

Improvements may reflect improved data reporting by the HMOs and increased provision of services. Improvements are still necessary in most areas of health care, but in particular dental services and behavioral health care. In addition, Medicaid coverage has expanded to include additional populations:

- **BadgerCare** is a Medicaid expansion program for families with higher incomes than Medicaid would usually allow. The funding for BadgerCare comes from a combination of federal Medicaid and CHIP, state GPR, and premium revenues.
- **Medicaid Purchase Plan**. Beginning in March 2000, people with disabilities who are working or interested in working are eligible to purchase Medicaid coverage by paying monthly premiums.
- **Family Care**. Four pilot sites have begun to provide managed long term care services to people who are elderly, to adults with physical disabilities, and to adults with developmental disabilities.

Beginning November 1999, Wisconsin Medicaid changed the policy on how Medicaid eligibility is determined for certain groups of individuals.

As a result of a case decision, the financial resources of a family member who is not the mother, father, or spouse of an individual cannot be used to determine that individual's Medicaid eligibility. Family members who were found ineligible for Medicaid due to too much income or assets, may now meet the Medicaid income or asset limits.

/2003/ There were no major systemic managed care expansions for the MCH population in 2001, but two major eligibility changes occurred in 2001. A mail-in application for "family Medicaid" was introduced in July, and the "asset test" was eliminated in October. Both of these changes, required due to a federal waiver, have expanded Medicaid eligibility for the target population. //2003//

/2004/ In 2002, no major systemic changes occurred regarding managed care for the MCH populations. However, a federal regulation became final in 2002 that may cause marked changes in Medicaid managed care in the future. These new regulations, published in final form on June 14, 2002, provide significant state authority to state

Medicaid programs to change their managed care systems. Much of the regulatory flexibility the rule allows is in keeping with the Bush Administration's "state's rights" agenda. However, to date, we have not been invited to provide any input on this comprehensive rewrite of managed care regulations for Wisconsin. This is in contrast to a comprehensive advisory committee process when the MA managed care system expanded statewide in the late 1990s. Some health care advocates, such as the National Health Law Program, have criticized the June rule as lacking many of the consumer protections and rights contained in a previous version of the rule, issued by the Clinton Administration in January 2001 ("the January regulations.") Thus, many key areas of managed care protections in the current Wisconsin MAP system, such as choice of managed care provider, notice and information requirements, grievance and appeals, and regulations regarding enrollees with special health care needs, appear to be at risk.

Another change in Medicaid managed care as it affects MCH relates to a reduction in the percentage of low-income families in the managed care system. When HMOs were introduced statewide in the 1990s, the Wisconsin Medicaid program referred to the new system simply as a "managed care system" for low-income families on Medicaid – as if the fee-for-service mode would become a relic of the past, or at least an insignificant consideration. However, because of continued volatility in Wisconsin's managed care marketplace, only about 72% of "family Medicaid" recipients are treated by managed care firms. A significant minority – 28%, or about 126,000 recipients as of March 2003 – were fee-for-service recipients. This holds significant implications for populations who favor the flexibility that fee-for-service Medicaid provides. In particular, families of children with special health care needs often prefer not having to deal with managed care prior authorizations. //2004//

*/**2005**/ The number of Medicaid managed care organizations has declined to 13 participating plans out of the state's 21 HMOs. According to an informational paper by the Wisconsin Council on Children and Families, Medicaid may need to increase payments to HMOs in order to retain them. The last contracts with the HMOs expired at the end of 2003, although the department invoked a clause renewing the contracts for another four months. Medicaid HMOs are significantly less expensive than fee-for-service care; according to the Department of Health and Family Services (DHFS) figures, HMOs are receiving $1,656 per enrollee per year, compared with average annual cost of $2,800 for fee-for-service care. //**2005**//*

**Welfare reform (W-2)**

Community-based agencies, LPHDs, and families anticipated some of the impact during the five MCH Regional Roundtables that the BFCH conducted in the summer of 1998, prior to W-2's implementation.

Of the 94 directors who were asked about changes for mothers, children, and families in the last five years or their priority needs now, there were approximately 91 responses that mentioned W-2. W-2 has been described in Section III. A. Overview. This does not include child care or parent education needs in relation to W-2, which will be discussed separately.

From the LPHDs perspective currently, W-2 has meant "doing business" in a different manner, in many instances. For the most part, families are unavailable for services during typical working hours and many LPHDs have expanded to evening and weekend hours. They have done more outreach and in some instances, have taken services to the workplace, daycares, and schools. A big city LPHD director observed, "With families at work, we have had

to take services to where they are. Two examples for us are daycare centers and public schools." From a systems perspective, a positive effect is that some LPHDs are working more closely with community partners in an attempt to provide safety nets for high-needs families. In some cases, churches have become more involved.

Nonetheless, directors comment that families are difficult to access because of limited time and the general struggle of managing work, home, and children, to say nothing of health care appointments for prevention efforts. For these families, preventive care is a luxury, not a necessity.

W-2 has ensured that almost all parents are working, as reported by the directors. However, many women work for minimum wage and may work 2nd or 3rd shift with 12 hour shifts or enforced overtime; the norm in several counties. Some employers do not allow time off for health care appointments. However, another county said that W-2 "created a viable workforce."

LPHDs have responded by expanding to evening and weekend hours, working more closely with their human or social service department, developing collaborations and coalitions with agencies and organizations to help meet the MCH population's changing needs.

/2003/ The national recession appears to have increased the W-2 caseload in Wisconsin. Observers believe that because of the strong economy that was in effect when W-2 began enabled a significant decline in W-2 participation. Former AFDC recipients were able to find jobs in the private economy easily. Conversely, the effects of the recession have had the opposite effect. In 2001, the statewide W-2 caseload increased from 10,911 in December 2000, to 12,259 in December 2001. The fact that caseloads have turned upward after the significant decline in the late 1990s is cause for concern in light of the changes noted by LPHD directors. //2003//

/2004/ The continuing economic downturn appears to be contributing to increased W-2 caseload numbers. In 2001, the statewide W-2 caseload increased from 10,911 in December 2000, to 12,259 in December 2001, to 14,137 in December 2002. Of that total, 78% of the cases were in Milwaukee County. The fact that caseloads have increased after the significant decline in the late 1990s is cause for concern in light of the changes noted by LPHD directors. //2004//

***/2005/*** *Even as the national economy improves, the statewide total W-2 caseload numbers have continued to increase. As of April 2004, Wisconsin Works total caseloads have increased to 15,226 in Wisconsin. Of that total, 79%, or 12,028 cases, are in Milwaukee County, the state's most populous county. The fact that caseloads continue to increase may be attributed to the fact that Wisconsin, with its relative dependence on the manufacturing sector, has been particularly hard-hit by manufacturing job losses. Also a potential factor is that, beginning in late 2002, the Department of Workforce Development (DWD) began to implement its "informed choice" administrative philosophy to replace the previous "light touch" philosophy. The latter "light touch" had officially promoted the idea that "many persons do better with just a light touch; the new system should provide only as much service as an eligible person asks for or needs." However, many W-2 caseworkers interpreted this policy as meaning that they would not assist in enrolling participants in related support services, such as Medicaid and food stamps, unless the W-2 enrollee specifically asked for them. DWDs official statements had previously included the statement that "there are no entitlements," although Medicaid has always remained a legal entitlement. In summary, the more*

*service-oriented "informed choice" approach may be responsible with enrolling more participants into W-2 and related programs such as Medicaid and food stamps. //**2005**//*

**IMPACT OF EMERGING ISSUES**

**Bioterrorism**

The Title V MCH/CSHCN Program provided strong leadership, starting on September 11th, 2001, to make sure that the long-term public health response to and preparation for terrorism would address the intense and pervasive stresses affecting children and families. This stemmed from immediate and ongoing recognition by Title V that the September 11th attacks and their aftermath have led people to pose deeply personal and communal questions. Children, families, and communities are re-assessing their understanding of the meaning of their lives and of their connections with one another. What do we value most in life? How can we better incorporate such values into our daily lives and our plans for the future? How can we pass along those values to our children? These questions have profound implications for public health, and Title V has assumed a leadership role in raising awareness and supporting people in this quest.

Title V's contribution to the role of public health during the post-September 11th times challenges us to make people aware of the fact that terrorism intends, as its primary goal, to fill people with overwhelming fear. Fear, unchecked, has repeatedly resulted in a downward cycle of polarization and violence that destroys the essence of community life and severs the bonds connecting us to each other. As such, it fractures the health and safety of the public, and especially the bonds so integral to the health and safety of children. Children with special needs and children affected by racial, ethnic, and economic disparities are particularly vulnerable. Title V has repeatedly emphasized that the public health response to terrorism must include a plan to foster ways for families and communities to face fear and transform it into hope.

MCH staff developed a set of messages to serve as a guide for dealing with feelings of fear, uncertainty, anxiety, and sadness in the wake of September 11th and our country being at war. These messages have been widely distributed throughout the state – on the Health Alert Network, the website of the Wisconsin DHFS, and in numerous newsletters. Crafted for adults, for parents/teachers/caregivers, and for children, the messages are based on a set of ideas drawn from both national and international research, such as resiliency and social capital. We actively participated in the development of the Center for Disease Control and Prevention (CDC) and HRSA funded bioterrorism grants, specifically incorporating mental health into the plan and focusing on how to equip families and communities with tools to help them sustain their health during this time. Furthermore, a strong collaboration between the Divisions of Public Health and Supportive Living has emerged from these efforts, and MCH and CSHCN staff are actively engaged in developing the state's overall mental health plan to deal with terrorism.

/2004/ The Title V MCH/CSHCN Program continues to collaborate with the new Division of Disability and Elder Services (DDES), Bureau of Mental Health and Substance Abuse Services on the Mental Health portion of the CDC funded bioterrorism grant. Major objectives and action steps have been created and are included separately or combined within other sections of the grant as appropriate. Currently, the process for hiring staff persons to implement our objectives and continue with creation of the state's overall mental health and bioterrorism plan is under way. As a result of our collaboration, this past fall, staff from the Title V MCH/CSHCN Program were

included in a workgroup held by the Division of Supportive Living (DSL) to create a plan for and apply for a grant from the SAMHSA Mental Health/ Substance Abuse Emergency Response. Presentations on "Preparedness for Crisis and the Mental Health of Children" have been held at several statewide conferences- building on the messages that were crafted by the Title V MCH/CSHCN Program after the September 11th attacks. //2004//

***/2005/*** *MCH received funds to negotiate 2004 bioterrorism objectives with the LPHDs. These objectives are to identify the unique needs of their local jurisdiction's maternal and child health populations during a public health emergency for inclusion in the Special Populations Section of the Consortium Public Health Preparedness and Response Plan.*

*In 2004 collaboration between The Title V MCH/CSHCN Program and the DDES, Bureau of Mental Health and Substance Abuse Services on the Mental Health portion of the CDC funded bioterrorism grant continued. A workgroup was convened and 'Wisconsin's Emergency Human Services Response: A Disaster Mental Health, Substance Abuse, and Human Services Plan' was a result of this effort. MCH and DDES staff also created a web CT course titled 'Disaster Mental Health and Emergency Preparedness and Response'. The web-based course is part of a larger state response team training intended for hospital workers, public health workers, and community partners.* ***//2005//***

**Child care**

In discussing changes over the last five years and current priority needs, directors mentioned child care approximately 59 times and in almost all cases connected their responses to the needs. Two director comments were "Moms are desperate searching for child care." and "There are no before or after school activities – children as young as five are left alone".

Child care issues mentioned by directors include too few licensed and certified daycare centers; untrained providers; not enough infant care slots; and little before or after school care. There is also little evening care or coverage for 3rd shift workers. Care for sick children is spotty and is compounded by some employer's intolerance for parents' staying home with sick kids. There is also a lack of child care geared to children with special needs. In the absence of center care, children may be left unsupervised or care is patch-worked together so that many caregivers get involved in a child's life. Often, mothers turn to their family support system and have grandparents, fathers, or neighbors provide child care.

W-2 and the resulting increased focus on child care in a child's life is contributing to a shift in the public health delivery paradigm. Says the director of a large metropolitan LPHD, "Child care providers have become key partners in public health service delivery. Children are, by and large, no longer at home and we must assure that their health needs are being met where they are."

/2003/ Access to quality child care continues to be a need for many families in Wisconsin. The Title V MCH/CSHCN Program continues to work with state partners to improve health linkages with child care colleagues as well as fund LPHDs to provide TA to local child care providers.

For state budget years 2001-03, $218 million was added to the child care subsidy program. Funding for child care licensing was increased. However, four licensing positions were deleted. The quality improvement grant program

was eliminated and the Child Care Resource and Referral (CCR&R) budget was reduced. Funds were added to the child care scholarship and bonus programs; TEACH (scholarships for child care workers); REWARD (stipends to child care workers with certain educational levels); and to create a mentoring program. The Early Childhood Excellence Initiative will continue but with decreased funding. //2003//

/2004/ The proposed 2003-2005 biennial budget contains several cuts in funding for child care. Administrative funding for the state child care office is cut 10% and two positions in the DHFS Bureau of Regulation and Licensing are converted to funding from license fee revenue. CCR&R agency funding is cut by 10%, the child care pass through grants (local collaborative grants) are cut by 75% and the safe child care program (to increase safety and health in certified child care homes) is eliminated.

The child care subsidy program (Wisconsin Shares) is reduced by $11.9 million in 2004 and by $14.1 million in 2005. TEACH (scholarship program) and REWARD (stipend program) are eliminated, although the governor has asked that $2.3 million in each year be used to partially restore this funding. The Early Childhood Excellence Centers have funding reduced from $7.5 million/year to $2.5 million/year. //2004//

***/2005/*** *The "Governor's Plan to Invest in Wisconsin's Future - "KidsFirst"" includes a proposal to improve the quality of child care by: 1) rating child care settings, and 2) informing parents of these ratings so they can make informed choices when making child care decisions. A task force is being formed by DWD, Office of Child Care to explore both quality indicators and tiered reimbursement. DHFS personnel, including MCH staff, will participate as part of this task force.* ***//2005//***

**Immigrants, refugees, and minorities**

In the 2000 MCH needs assessment 30 references were made to the relatively rapid influx into many counties of immigrants, refugees, and minorities by directors in response to discussion about five year changes and priority needs. Groups mentioned include: South Americans and other Hispanics, Bosnians, Kurds, Croatians, Albanians, Kosovanians, Koreans, Hmong, and Amish. Directors perceive that the numbers of people in these new populations is growing.

In addition to wars and ethnic strife around the world, several directors hypothesized that with relatively full employment in the state, these immigrants fill a need for low-cost employees in farm work and meat packing plants. Few have insurance or qualify for public payment programs and, as mentioned above, this increases directors' concerns regarding access to basic preventive health and dental services. Some immigrants have had very little western-style health care provided in their lives while family members may be knowledgeable about traditional folk care giving. Many have major health problems, often undiagnosed. TB is a concern, among other diseases. One county was concerned that the immigrants would skew their health statistics.

Providing care is described as labor intensive and frustrating, both because of language and cultural barriers and because of families' resistance to services. Not only do LPHD directors feel they need teaching methods and materials in new languages, many say they are unable to find interpreters or translators in the language required, to say nothing of the funds to pay for these services. Several directors mentioned the problem of community acceptance of newcomers, the county's previous lack of diversity, and their own need for training in providing culturally competent service.

Directors shared some poignant stories about meeting these newcomers' needs. Some examples are shared as follows:

> "Our Hispanic population has very high needs and few resources. We provide prenatal care coordination-like services using MCH funding. If we did not do this, these women would come to the hospital with no prenatal care."
>
> "We have worked slowly in building trust with and showing respect for the new Amish families who have moved here. We are now able to provide immunizations and dental exams as well as postpartum and well child exams. This would be unheard of in some Amish communities."
>
> "We teamed up with Head Start and Migrant Health Services to set up daycare for farm workers." Another: "We provide a huge amount of time and support to our refugee families. We make sure they receive the health services they need."
>
> Finally, "Nine extended family members came as a group to our county to milk cows. They all live in one house. A young woman in the group was pregnant. We got her into prenatal care and on to WIC. Our MCH nurse, although not Spanish speaking, took the mom to the grocery store to help with shopping. This is the first non-English speaking family in our county so residents were a little leery."

/2003/ As we strive to eliminate health disparities in Wisconsin, we are challenged to develop policies that reflect a partnership among all who have a stake in the future health and safety of children and families. As MCH professionals, we are learning to listen more inclusively to the people that we serve in the design of policies to address disparities. We are learning to move away from a paradigm that tends to be primarily rooted in risk reduction to a paradigm rooted in building healthy communities. We are coming to understand that as public health practitioners, we are, like all people, ethnocentric – we have our own cultural framework that shapes the way we do business. We are realizing that to eliminate racial, ethnic, and class disparities, we all must come together and focus on common ground as a foundation for action and policy.

The former United States Surgeon General, Dr. David Satcher, established Year 2010 public health objectives of 100% access to health care and zero disparities in health status for all citizens. Healthiest Wisconsin 2010 is in strong alignment with these objectives. The attainment of such an ambitious and significant public health objective depends on the capacity of all of our health systems to deliver culturally and linguistically competent care. Rapid change in the organization and delivery of health care and the increasing diversity of the population heighten the importance of striving to incorporate cultural competence into the provision of health care.

MCH practitioners are well poised to play a central leadership role in this effort, and many have already done so. First, they can educate themselves on this issue. Second, they can advocate within their own organizations for policy changes that place a value on diversity, implement frequent cultural self-assessment, are conscious of the dynamics inherent when cultures interact, and put into practice adaptations to service delivery that reflect an understanding and honoring of cultural diversity. Finally, they can collaborate with diverse partners to ensure that their communities recognize cultural competence as a high priority and foundation for healthy and safe children and families.

Title V uses the 1989 monograph, "Toward a Culturally Competent System of Care", for its definition of cultural and linguistic competence. According to this definition, cultural competence is a set of behaviors, attitudes, and policies that enable a system, organization, or medical practice to work effectively in cross-cultural situations. Culturally sensitive health care involves the individual provider's awareness of and respect for the beliefs of people of various backgrounds. Cultural competence, on the other hand, encompasses such awareness and respect at the institutional or organizational level.

The Title V MCH/CSHCN Program believes that an organizational self-assessment and awareness of the impact of an organization's culture on services to families are central to getting started in the practice of cultural competence. In fact, we affirm the process of self-assessment as more important than what it may in fact demonstrate. We do this because we realize that the path to culturally competent practices follows a long continuum ranging from cultural destructiveness to cultural proficiency, and that agencies are currently at multiple stages in this process.

To put this principle into practice, the Title V MCH/CSHCN Program encourages all of its statewide funded projects address a set of activities to demonstrate their commitment to culturally and linguistically competent practices. MCH staff work with the Title V funded statewide projects to encourage them to assure that, in their work plans, they do the following:

- Set aside resources for culturally competent services and policies with detailed justification for the amount to be spent.
- Demonstrate work done to become more culturally competent.
- Describe how these are put into practice through training, job descriptions, hiring practices, program guidelines, mission statement, staff evaluations, consultants, subcontractors, and modes of communication within the agency and with recipients of services.
- Include people of diverse cultures in all partnerships and collaborations.
- Use evaluation methodologies that draw on input from the diverse cultures in the community and reflect a sensitivity to cultural behaviors, attitudes, and preferences.
- Document written policies and procedures that address communication needs such as easy to understand educational materials (written, oral, and visual) and translators who can communicate at a skill level that is conversational and respectful of the culture.
- Incorporate culture-specific medical practices, spiritual healing, and traditional beliefs.
- Move toward a staffing pattern that reflects the diversity of the community.
- Include questions about cultural competence in the hiring process.
- Integrate cultural celebrations into day to day operations. //2003//

/2004/ Healthy Babies in Wisconsin: A Call to Action will be held July 15, 2003. Careful planning has gone into this statewide perinatal summit to develop new approaches to address disparities in the area of perinatal health. Our Black/White infant mortality gap is widening. Current programs are not taking us where we want to go. We can do better! The summit will encourage participants to examine their programs and community needs and identify priorities and concrete solutions. Key strategies include:

- <u>Partners</u>

Consumers from the two federal Healthy Start projects and other sites will be involved in the summit as participants and presenters at breakout sessions. LPHD directors will be asked to also invite people in their community who could help champion local and regional efforts to improve birth outcomes. Other key partners include representatives from hospitals, community health centers (CHCs), HMOs, community-based organizations, the faith community, educational institutions, media and legislators.

- A New Framework

  The State Health Plan and the Perinatal Periods of Risk model will provide the framework for ongoing activities. The PPOR methodology assigns fetal and infant deaths to one of four categories based on the time of death and weight at delivery. Each category is associated with specific public health interventions to reduce the likelihood of fetal and infant deaths. The PPOR model also looks at what is possible by calculating death rates for a reference population with good outcomes such as white women, 20 or more years of age with 13 or more years of education.
- Regional Call to Action

  After hearing strategies from national speakers, state and local data, and the stories behind the numbers, summit participants will meet in regional teams for strategic planning. Following the summit, regional forums will be held to mobilize additional partners, continue planning efforts, and implement solutions that are based on regional data and sustainable over time. //2004//

***/2005/*** *Following the Healthy Babies in Wisconsin Summit in 2003, Action Teams formed to support sustainable activities to improve birth outcomes and address disparities. Five regional teams are meeting to identify additional partners, share successes and needs, and plan strategies to improve the health of mothers and babies in Wisconsin. An Action Team focused on Native American families is under consideration. In addition, an Action Team Meeting was held May 10, 2004 to address Racial and Ethnic Disparities in Birth Outcomes. This meeting brought together approximately 160 public health providers, consumers, educators, hospital administrators, and representatives from community-based organizations to focus on disparate African American IMRs in targeted Wisconsin cities. Participants identified collaborative partners and action steps to address disparities.* ***//2005//***

**Mental Health**

Many directors mention concern about a variety of mental health issues including increases in mental illness, cognitive delays, and suicide.

Adolescent substance abuse, teen homelessness, and child abuse and neglect are of concern. An increase in family dysfuntion, apart from the W-2 issues mentioned, is perceived.

/2003/ MCH staff have recently become involved in a variety of efforts to address mental health. Activities include a statewide infant mental health initiative, parental and infant mental health trainings for POCAN projects, a planning document by the Mental Health Association of Milwaukee, and a statewide group addressing the Turning Point Healthiest Wisconsin 2010 objective of stigma reduction related to mental health. Planning is underway for an MCH Symposium that will gather a wide diversity of people statewide to learn about state-of-the-art approaches to key issues in family and community health and to engage in dialogue about ways to translate this information into action. The first symposium will address the Healthiest Wisconsin 2010 priority of mental health as it applies to the

MCH population. The Title V CMO formed a workgroup that creates a partnership within DHFS between MCH and the mental health and substance abuse bureaus within DSL. A key factor driving these efforts is our increased recognition of practicing MCH within the interlinked ecological context. The interlinked ecological context refers to the role of caring human relationships, social support networks, social capital, humane health systems and policies, and a heightened sense of community in improving family and community health and eliminating disparities. Children and families who receive consistent affirmation of their dignity rather than constant reminders of their level of risk are more likely to develop resiliency that can enable them to thrive in spite of social and economic stresses. //2003//

/2004/ Staff continue to be involved in a variety of efforts to address mental health. The Wisconsin Initiative for Infant Mental Health Summit brought together parents, key leaders and practitioners in the areas of clinical/medical services, academia, advocacy, policy, child care, early intervention, and early childhood education. MCH staff participated in the summit planning committee as well as the summit itself. The summit's purpose was to begin the state wide Early Childhood Mental Health Plan process. Parental and infant mental health training for POCAN projects continue.

The Wisconsin Association for Perinatal Care has formed a Perinatal Depression Task force which has been doing work statewide. The Task Force produced an educational video "More Than Just the Blues" for health care providers. The video emphasizes the need for screening. Interviews with women who have suffered postpartum depression share their personal stories and thoughts on interventions that may have helped them. The video is part of educational sessions being held around the state at regional meetings of the Association of Women's Health, Obstetric, and Neonatal Nurses. Others activities to increase awareness and knowledge of perinatal depression include large informational ads on the sides of buses in the Madison area and the translation of the More Than Just the Blues brochure into Spanish and Hmong. The Wisconsin Association of Perinatal Care is supporting efforts to pilot test routine screening of pregnant and postpartum women for depression. In addition, the Perinatal Foundation hosted a Perinatal Mood Disorders conference on June 10th with internationally known speakers.

Staff also continue to be involved in the group addressing the Turning Point Healthiest Wisconsin 2010 objective of stigma reduction related to mental health, which is now named Wisconsin United for Mental Health (WUMH). //2004//

***/2005/*** *The Wisconsin Initiative for Infant Mental Health completed a state wide plan for a comprehensive infant and early childhood mental health system of care. This blueprint was highlighted in the "Governor's Plan to Invest in Wisconsin's Future – Kid's First" with the directive to implement the recommendations as outlined. Through many partners, including MCH and CSHCN, the goal is to incorporate childhood social and emotional development into all systems that touch the lives of young children including child care, early education, child welfare, children with special health care needs, and early intervention programs.*

*The work of the Perinatal Depression Task Force continues with educational sessions and dissemination of the "More Than Just the Blues" video and multi-language pamphlets. As a follow-up to their 2003 conference on Perinatal Mood Disorders, the Perinatal Foundation released "A Blue Print for Action". The report addresses issues including stepped care, the role of stress in perinatal depression, public health partners, maternal-infant*

*bonding, immediate and long-term effects of maternal depression on the infant and family, perinatal treatment modalities, and lessons from mothers experiencing perinatal depression. The Perinatal Foundation will collaborate with the Wisconsin Association for Perinatal Care in 2004 to provide regional conferences on "Perinatal Mood Disorders: You Can't Tell by Looking." The educational sessions will disseminate best practices for the identification and treatment of women and families who experience perinatal mood disorders and promote integration of best practices among regional health care providers and systems.*

*Staff continue involvement with the Mental Health Transition Advisory Council (MHTAC). This council's mission is to develop and implement a comprehensive plan to assist adolescents with emotional disorders and/or mental illness achieve a successful transition to the adult mental health services they need and to the highest level of independent living they are capable of attaining. Staff involvement with WUMH continues.* ***//2005//***

**Access to health care**

In the discussion regarding five year changes and priority needs, directors attributed 62 responses that concerned problems in accessing care, inadequate or no health insurance, provider scarcity, or issues with HMOs. Some access issues relate to increased numbers of immigrants who don't have a payment source, others to employers not providing insurance for W-2 clients, farm families being unable to afford adequate insurance, or a shifting managed care environment.

Says one director, "Our BadgerCare/MA outreach has been quite successful. One idea we came up with was distributing a recipe card to the public with outreach information on the back of it and families really responded!" Another, "BadgerCare outreach has helped families in our county." Finally, "We have higher rates of insured families because of BadgerCare." Directors commented about the summer GuardCare program that offers preventive health service in targeted communities on several weeks during the summer, saying "That's the best thing on the horizon for meeting uninsured families' needs." and "Our GuardCare program provides free dental and medical access."

Many directors puzzle that HealthCheck (EPSDT) exams have decreased in their counties and some are not sure why. Numerous others, however, feel that HealthCheck exams provided by HMOs are minimal and that managed care lacks a prevention focus. One director comments, "80% of the children in our rural county should be getting HealthCheck exams. The doctors aren't doing them and our agency doesn't have the capacity to meet all that need". Another says, "We have to fight for basic services."

In some parts of the state, primary providers are scarce, making insurance status a moot point. Hospitals may be far distances, making transportation a major problem. High emergency room usage is mentioned. Several directors said they have no OB providers in their counties. One commented, "Moms are sometimes not seen until the 2nd trimester because of travel distance and difficulty getting in." Another, "Our HMO has severe delays for appointments – there was a two month wait for a 15 year old in her 3rd trimester." For some children, the only source of health care is what is offered in the schools. Specialized care for teenagers and mental health services are non-existent in some locations. Another, "Families in our area struggle with a lot of challenges, one of which is few available physicians. Our health department does the best we can with very tight resources." In addition, medical nutritional therapy by a dietitian to children and youth ages birth to 21 is important.

/2003/ BadgerCare's enrollment growth continued in 2002 and early 2003, rising to a peak of 92,409 as of January 2003. In the state's 2001-2003 biennial budget, the Legislature enabled further enrollment growth by providing additional funding to increase the enrollment limit to 93,715.

However, a more accurate measure of access to health insurance for Wisconsin's low-income persons is the "family Medicaid total." This category combines both the CHIP program, BadgerCare, and the Medicaid enrollment of low-income families with children. This total rose by 54,887 in 2001, a 17.6% increase from a year earlier. Those parents who were laid-off from work who otherwise would qualify for BadgerCare may sign up immediately upon losing employer-provided insurance. A three-month waiting period, initially implemented to prevent "crowd-out" of private insurance, is waived in the event of involuntary job loss.

Another major change to BadgerCare in 2001 was the federal approval of Wisconsin's waiver request for enhanced Title XXI funding for enrolled parents. The waiver allowed 71% federal funding participation to BadgerCare parents as well as children. As part of the agreement, Wisconsin's BadgerCare program implemented simplified application processes, including a mail-in application. Also, the "asset test" was removed for all family Medicaid applicants.

More recently, Governor McCallum announced that Medicaid and BadgerCare would be exempt from cuts in his "budget repair bill" necessitated by an estimated $1.1 billion shortfall in the state's 2001-2003 biennial budget. //2003//

/2004/ BadgerCare's growth continued through 2002 and into the first quarter of 2003, rising to 106,654 in March 2003. It is driven by word-of-mouth and demand for health insurance caused by job losses. In the state's 2001-2003 biennial budget, the Legislature enabled further enrollment growth by providing additional funding to increase the enrollment limit to 93,715. As that biennium draws to a close, Wisconsin's CHIP program remains "open for enrollment," even though the state now struggles with a $3.2 billion budget deficit. The program appears to maintain its bipartisan support in the Legislature. In March 2003, BadgerCare's enrollment stood at 106,654 – or 13.8% greater than the biennium's budgeted amount. Of that total, 71,108 are adults and 35,546 are children. However, one must note that BadgerCare's popularity has also driven "family Medicaid" in Wisconsin higher, because the state's enrollment system seamlessly categorizes family members into either BadgerCare or Medicaid. "Family Medicaid" combines both the CHIP program, BadgerCare, and the Medicaid enrollment of low-income families with children. Total "family Medicaid" enrollment in 2002 increased 14.9% from December 2001 through December 2002. A measure of BadgerCare's overall positive effect in insuring low-income children and families is that family Medicaid has doubled from July 1999 – the date of the CHIP program's inception – through January 2003. In January, the family Medicaid total stood at 431,261. //2004//

***/2005/*** *Medicaid and BadgerCare continue to help provide access to care for low-income people in Wisconsin. In April 2004, the DHFS Secretary distributed a news release saying that 97% of the state's children have health care coverage. Overall, 800,000 Wisconsin residents – more than one in seven – have coverage related to Medicaid or BadgerCare. Nearly 480,000 family members, including 307,000 children, are covered through family Medicaid. Despite the obvious budget implications of the strong enrollment growth, Governor Doyle and the Legislature have maintained their support for the safety-net programs. In his "KidsFirst" initiative announced in May 2004,*

*Governor Doyle reiterated his support for continued Medicaid outreach among minorities, in particular. In his "State of the State," Governor Doyle has contrasted Wisconsin's continued "open enrollment" policy for Medicaid and BadgerCare to other states' significant cuts in enrollment, or in Medicaid scope of services, or both. Despite this support, containing Medicaid costs will remain an issue in the upcoming 2005-2007 state budget deliberations. //**2005**//*

**Access to oral health**

Access to dental care is one of Wisconsin's most pressing needs. CHAW conducted a survey in 1998 of programs around the state that provided dental care or access to dental care for the uninsured and underinsured including those covered by the Medicaid program. The handbook, *Dental Care Access Programs for the Uninsured and Underinsured in Wisconsin,* August 1998 revealed that it is difficult to find dentists who are willing to participate in the Medicaid program for various reasons. In 1998, 93% of Wisconsin's children had health coverage; however only 25% of the children covered by Medicaid saw a dentist.

Results from the 2000 Needs and Strengths Assessment showed that there were 44 times that access to dental care was mentioned as a change in the last five years or a current priority need. In addition to the issues already mentioned with Medicaid this extends to BadgerCare, with directors feeling that… "having BadgerCare has not helped in getting dental care for kids." Directors repeatedly commented that most dentists in their area would not see anyone with a Medicaid card. "We polled 30 dentists in our county and all surrounding counties and none would take Medicaid or BadgerCare," says one director. Another said jubilantly, "We have a new dentist who takes Medicaid! But there is a huge waiting list." An additional problem is that the mal-distribution of dentists parallels that of physicians so in many regions there simply are not enough dentists to meet rural families' needs.

LPHDs have attempted to respond to the dental access crisis in creative ways, although it is often reported to be when the child has an infection and needs emergency care. One director says, "We quickly found money from the Salvation Army to pay for a child's dental needs." Another reports, "We applied for a rural health grant that funds dental hygienist students to provide exams and basic preventive services." Another, "We located a retired dentist who will see special needs children in our area."

/2003/ In 2001, DPH hired an oral health consultant. Through a grant from the CDC, DPH conducted a statewide, representative random sample of 3,307 third graders as part of the "Make Your Smile Count Survey" within the DPH Regions. Key findings show:

- 60% of the children had a history of dental caries
- 31% of the children had untreated decay
- 47% of the children had at least one permanent first molar with a dental sealant
- 31% of the children screened needed restorative dental care: 27% were in need of early dental care, while 4% needed urgent dental care

The percent of children in need of dental care is assumed to be an underestimation because dental radiographs were not taken. //2003//

/2004/ Additional key findings of the Make Your Smile Count Survey that were released include:

- Children surveyed who attended lower income schools had significantly more untreated decay (44.5%) compared to children in both middle (31.7%) and higher income schools (16.6%).
- Children attending lower income schools were less likely to have dental sealants (33.5%) compared to children in both middle (49.9%) and higher income schools (56.6%).
- 8% of the children in lower income schools were in need of urgent dental care, compared to children in middle (2.2%) and high-income schools (1.5%). //2004//

***/2005/*** *No significant changes.* ***//2005//***

**Availability of specialty services**

Wisconsin's Medicaid capitated health plans are not required to provide children with special health care needs access to a pediatric specialist as their primary care provider (PCP). In addition, these plans are not required to refer these children with specific medical conditions to a specialist without first seeking a referral from their primary care physician. However, the five categories of children with special health care needs, as defined in the Balanced Budget Act of 1997, are able to opt out of Wisconsin's capitated health plans and obtain Medicaid covered services in a fee-for-service environment.

Existing resources for specialty care that is community-based: Wisconsin does boast several large specialty clinics/hospitals (St. Joseph's Hospital-Marshfield Clinic, Gundersen Lutheran Medical Center - LaCrosse, Children's Hospital of Wisconsin in Milwaukee, and UW Hospital and Clinic in Madison). However, access to these specialty services is oftentimes more difficult for rural populations, regardless of Medicaid eligibility or insurance carrier.

/2003/ No significant changes. //2003//

/2004/ No significant changes. //2004//

***/2005/*** *The Community Integration Program 1A/B Waivers, Traumatic Brain Injury Waiver, and the Children's Long Term Support Waivers were submitted to the federal Centers for Medicare and Medicaid Services (CMS) for review under the Medicaid rules that permit states to flexibly use Medicaid funds for community supports and services. These waivers are called home and community-based service (HCBS) waivers. The waivers give the State the flexibility to design, develop, and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities, or intermediate care facilities for persons with mental retardation. Wisconsin DHFS has a variety of services with the children's waivers. DHFS included the intensive in-home autism service with their waiver application.*

*A variety of services are available under the children's waivers. If a child is receiving intensive in-home services, this is the only waiver service delivered. If the child is in the ongoing waiver, CMS has approved the following types of services: adaptive equipment, counseling and therapeutic resources, respite, home modifications, specialized transportation, family-directed services, family-centered services, and day services related to supported employment as well as child care.* ***//2005//***

**LINKAGES**

**Birth to 3 and CSHCN**

Many LPHDs are seeing more special needs children, their numbers are perceived to be increasing, and there is greater complexity in these children's care. In some areas, home care is inadequate. Again, children seem to have greater developmental needs and there is a perception that autism may be increasing.

/2003/ The CSHCN Program and the Birth to 3 Program (within DSL) have formed a collaborative relationship which includes:

- Establishing an information and referral hotline.
  - Wisconsin First Step as a centralized statewide information and referral hotline and website serves as the central directory for both the Birth to 3 Program and for the Regional CSHCN Centers. First Step provides callers and website users direct access to information and referral sources and also provides callers direct referrals to either program (1-800-642-7837 and **www.mch-hotlines.org**). The telephone line is operational 24 hours a day, seven days a week. Parent Specialists with specialized disability expertise and who have a child with a special need answer the line Monday-Friday, 8:00 a.m. to 4:00 p.m. The Birth to 3 Program and the Title V MCH/CSHCN Program Block Grant share in funding this toll free service. See Section III. A. Overview and / or Section IV. E. Other Program Activities – Discussion of Toll-Free Hotlines.
- Providing reciprocal committee representation (not all inclusive).
  - Birth to 3 Interagency Coordinating Council (ICC). Governor appointment of the CSHCN Program Medical Director.
  - Infant/Young Child Nutrition Coalition which is lead by the CSHCN Nutritionist.
  - Wisconsin Personnel Development Project (WPDP) Birth to 3 Advisory Committee.
  - Birth to 3 and UNHS Best Practice Committee and CSHCN UNHS Implementation Workgroup.
  - Regional CSHCN Center Director's meetings.
  - Council on Birth Defect Prevention and Surveillance Council. DHFS Secretary appointment of a Birth to 3 representative.
  - Monthly meeting with Title V, Medicaid, and Part C to coordinate policy and funding.
- Assuring collaboration for conferences.
  - Provide financial and staff support to the Circles of Life Conference (Annual Family and Provider Conference) and the Birth to 5/ Wisconsin Early Childhood Association Conference.
  - Through MCHB grant dollars received by the CSHCN Program, the state Birth to 3 Program subcontracts with the WPDP - Waisman Center to provide opportunities to Birth to 3 county providers. Through this mechanism, the WPDP has provided training to Birth to 3 providers regarding UNHS, and infant hearing and has created a network of regional experts in intervention for the hearing impaired.
- Providing in-kind support on several grants.
  - MCHB Grant that supports the WSB program.
  - CDC Grant for EHDI Data and Tracking Initiative known as WE-TRAC.
  - CDC Grant to support efforts for the Birth Defects and Surveillance Program training. //2003//

/2004/ Due to the DHFS reorganization following the election of a new governor and new DHFS secretary, the Birth to 3 Program is now located in the DDES. Also, the CSHCN Medical Director and Nurse Consultant sit on a Birth to 3 Program Health and Medical Outreach Committee that aims to better coordinate early intervention and medical services for children participating in the Birth to 3 Program. No other significant changes. //2004//

***/2005/*** *No significant changes.* ***//2005//***

**Native Americans: "Honoring Our Children (HOC) with a Healthy Start"**

The Title V MCH/CSHCN Program first alerted GLITC to the opportunity for Healthy Start funds and assisted them with their successful application in 1997. The State Maternal/Perinatal nurse consultant attends all the Advisory Board meetings, provides TA on services to high-risk women, and consults with the analyst who does the required data analysis and reports. The project chose to use our SPHERE data system for all its federal Healthy Start reporting requirements.

The HOC Project provides enhanced perinatal/infant care coordination services to families in nine tribes. It has been a great challenge to coordinate a program across nine autonomous tribal nations spread throughout the state. Each tribal nation has different resources; some have seen large revenues from gaming while others have not. The health problems remain consistent, with tobacco use during pregnancy and in homes with young children a major focus of intervention. Successes are notable: data from 2000 found that project infants had lower rates of low birthweight and prematurity than the state average; 32% of project infants were breastfed for three months or longer; and there were no infant deaths.

/2003/ In the fall of 2001, the chief responsibility for directing the HOC Project shifted. The Title V MCH/CSHCN Program assisted with the transition phase. //2003//

/2004/ In 2002, the HOC Project has served 70% (284/408) of the population of pregnant women; 45% (208/461) of the population of postpartum women; 88% (511/578) of the population of infants up to the two years of age; and 80% (227/284) of pregnant participants who initiated prenatal care in the first trimester. Case management services were provided for: 88% of pregnant women; 88% of postpartum women; and 82% of infants. Ninety percent of pregnant women served were identified as high-risk and 76% of postpartum women and infants were high-risk. Regarding birth outcomes (total number = 224): 4% were low birth weight; 1% were very low birth weight; 7% were preterm; 1% were small for gestational age; and 10% were large for gestational age. Approximately 64% of all postpartum participants received interconceptional services and 5% of families received mental health referrals prior to an initiative to screen for perinatal depression. Education was provided to project staff, families, consortium members, and service providers. Of the families served, 66% had smoking occur in their households. //2004//

***/2005/*** *In 2003, 595 families participated in the HOC Project. Services included: prenatal case management (285 program participants), case management in the interconceptional period (455), prenatal outreach (210), prenatal home visits (419), home visits in the interconceptional period (290 program participants), pregnancy prevention activities for adolescents under the age of 17 (15), pregnancy/childbirth education (228), parenting skills building education (315), youth empowerment/mentoring program (4), transportation (117), translation (2), child care (62), breastfeeding counseling and support (244), nutrition education and counseling including WIC (725), male support (87), housing assistance (65), jobs training (56), and prison initiatives (15). In addition education was provided to*

*the community, consortia, and health care providers. Outcomes are not available at this time because of the late start-up of SPHERE, the electronic data system. //**2005**//*

**Family Gathering**

At the federal Healthy Start Grantees Meeting in Washington in 1998, we set in motion a plan to integrate the two Wisconsin Healthy Start Projects with other MCH programs, services, and systems in the state, including the perinatal system. From the start, we worked with MHBP and HOC in planning for three unique conferences held in the summers of 1999 and 2000 and the spring of 2001. They were entitled "Families Helping Families Gathering: Promoting Healthy Families and Infants through Healthy Start Projects".

/2003/ The 2001 Annual Gathering, held in June 2001 in Wisconsin Rapids, built on the momentum from the two previous gatherings. The providers who took part, including representatives from Title V, WAPC, and the IDC-W, were inspired by the cultural celebrations and family empowerment that again took place at the Gathering. A videotape is available from the Gathering. In addition, several family members from the two Healthy Start Projects are becoming strong advocates for systems change. For example, one family from each project has been involved, from the start, in a broad-based effort to hold a Wisconsin Perinatal Summit in 2003. //2003//

/2004/ The Fourth Annual Families Helping Families Gathering was held in June 2002 in Wisconsin Dells. Gathering participants have become strong advocates for systems change. Consumers from the MHBP have played a key role in planning a breakout session at the Healthy Babies summit on access to health care. HOC participants will be on a panel discussing breastfeeding issues. Other Healthy Start consumers will be invited to Healthy Babies in Wisconsin: A Call to Action. The 5th annual Gathering will be held on June 23-25, three weeks prior to the summit. This will allow a group of consumers to carry forward concerns and identified solutions from the Gathering to the perinatal summit. In addition, the Title V CMO has been invited to give a presentation on Title V and opportunities for collaboration. //2004//

***/2005/** The Black Health Coalition and the Great Lake Inter Tribal Council collaborated for the fifth consecutive year to host the Families Helping Families Gathering. The format of the 2003 Gathering was changed to provide more in-depth training on leadership development and sustainability. This was beneficial to those in attendance, the two Healthy Start Projects, and the communities. //**2005**//*

**Common Ground**

Milwaukee Common Ground started in 1993 with the Black Health Coalition as a participant and evaluator of the first conference held in March 1994. The project, based on the future search principles described by Marvin Weisbord and Sandra Janoff, held two more Future Search Conferences in 1995 and 2000, the purpose of which were to improve collaboration for reducing infant mortality in Milwaukee. Milwaukee Common Ground provides for a way of dialogue that is unique and often lacking in MCH work.

/2004/ No significant update. //2004//

***/2005/** No significant changes. //**2005**//*

**Population-Based Services and Infrastructure Building Activities are combined**

The following describes a number of priority health problems for high need MCH populations in Wisconsin.

**Asthma**

Asthma is a chronic lung condition affecting children and adults that can result in hospitalization or even death, as witnessed by recent news reports. In 1998, close to 6,000 asthma hospitalizations occurred in Wisconsin at a cost of $26,000,000. One-fifth of this cost was borne by Medicaid dollars. Many asthma hospitalizations represent repeat admissions for asthma that is not well self-managed and/or medically treated.

Wisconsin's racial minorities and children represent a disproportionate share of asthma costs. African Americans residing in Milwaukee's central city have asthma hospitalization rates up to eight times higher than the state rate, according to a 1994 review. Preliminary research suggests that 10% of urban school-age children have asthma. In Milwaukee, 16-29% of students at two high schools reported having asthma. Further, about 70% of asthmatic children in Milwaukee Public Schools do not have a written asthma self-care plan and two-thirds with persistent symptoms do not use appropriate control medications. The basics of asthma management are known to reduce hospitalizations and other health care utilization. In response to this emerging problem, we have planned that for CHAW to organize an asthma summit in 2000.

/2002/ A Summit conference on asthma was held in May 2001. It was well attended and received and CHAW will publish and distribute the Summit proceedings and will facilitate the work of the six subcommittees formed to work on the various aspects of the issue during the coming year.

/2003/ Following the Asthma Summit in May 2001, the WAC was formed. This includes a Wisconsin Asthma Executive Committee comprised of the six workgroup chairs, CHAW staff, DPH staff, and invited others. This Executive Committee met frequently to plan follow-up activities that included: the selection of a community planning model; the adoption of a format for meeting minutes and action plans; selection of a decision-making process; the establishment of ground rules for the workgroup meetings; and a timeline for the development, dissemination, and review of a Wisconsin asthma plan. DPH received a CDC planning grant which funds CHAW to coordinate and support the workgroups activities as well as a DPH Epidemiologist for surveillance, a state-level DPH coordinator and a DPH data manager. All workgroups convened on March 15, 2003. //2003//

/2004/ Each Wisconsin Asthma Coalition workgroup created objectives that ultimately will be combined to form the statewide asthma plan. The Executive Committee has been meeting monthly to formalize the Wisconsin Asthma Coalition processes. Listening sessions were conducted throughout the state to introduce the state asthma plan and the Wisconsin Asthma Coalition to community partners, professional health care associations, and interested groups. The Executive Committee and the workgroups met on May 9, 2003, to review comments received at the listening sessions, and to revise workgroup objectives as needed. //2004//

***/2005/*** *In 2003, the Wisconsin Asthma Coalition created and published the "State of Wisconsin Asthma Plan". In October 2003, the Wisconsin Asthma Coalition Executive Committee convened a meeting of the coalition members and community partners to unveil the completed Wisconsin Asthma Plan. The Asthma plan has been received favorably throughout the state, and membership within the coalition continues to grow. The Asthma plan was completed within two years of a three-year CDC planning grant, and because of this, we have been able to identify and initiate several implementation pilot projects during the third year of the planning grant.*

*The pilot projects include:*

1) *Providing education for legislators regarding the burden of asthma in Wisconsin. The Legislative Council is considering the selection and study of asthma in 2004. The Legislative Council Committee is made up of legislators and lay citizens who study a selected group of issues and offer a final report that includes legislative and policy recommendations.*
2) *Allergist Outreach Education to Primary Care Practices. This project is also funded by the Wisconsin Academy of Pediatrics Foundation through an unrestricted educational grant from GlaxoSmithKline. The objective of this education program is to improve asthma diagnosis and management by primary care clinicians and nurses.*
3) *Evaluation of educational materials. The education workgroup will collect examples of educational materials currently used throughout Wisconsin. Collected materials will be reviewed for usability and compliance with the National Asthma Education and Prevention Program Guidelines.*
4) *Low-sulfur fuel program. The Wisconsin Asthma Coalition will partner with the Wisconsin Department of Natural Resources and a school bus company in a metropolitan Milwaukee area, (an ozone non-attainment area), to provide low-sulfur fuel for the school buses.*
5) *Work-related asthma diagnosis guidelines and health history data collection instrument. A health history data collection instrument will be created. This instrument can be used by health care providers to assist in the diagnosis of work-related asthma and collecting information to assist in work-related asthma surveillance.*

*The Wisconsin Asthma Plan has overarching and specific goals with related objectives and action steps to address asthma in Wisconsin. For 2005, we have applied for an Enhanced Planning Grant from CDC to provide funding to continue the work of the Wisconsin Asthma Coalition and the implementation of the Wisconsin Asthma Plan. For the first year of funding, the Executive Committee has selected a variety of projects from the plan that will be implemented in the first year of funding. These include continuing the Low Sulfur Fuel program and the Allergist Outreach Educational programs, Fight Asthma Milwaukee (FAM) allies will provide neighborhood organizing in the African American and Latino communities, and the Menominee Tribal Clinic will offer the Allergist Outreach Education Program to its clinic staff. Small grants will be made available to local asthma coalitions for coalition development or to implement activities in their communities.* ***//2005//***

**Diabetes**

/2004/ In 2001, the CSHCN Program and the Diabetes Prevention and Control Program combined efforts to coordinate a statewide effort to develop, design, distribute and implement a resource guide for schools and families regarding care of children with diabetes while in school. In 1999, the New York Diabetes Control Program produced two manuals. We obtained approval from New York to modify their manuals for Wisconsin. A diverse group of professionals from public health, education, primary care, professional organizations, non-profit service organizations, parents, and students with diabetes, came together to work on this resource guide. We conducted several workgroups to review and modify the New York manuals to fit the needs of Wisconsin children with diabetes from 2001 through 2002.

In 2002, the resource guide for schools and families; “Children with Diabetes: A Resource Guide for Wisconsin Schools and Families” was published. The purpose is to help those working with children who have diabetes

understand the disease, basic diabetes care requirements, legal issues, and most importantly, their own personal role. The manual contains supporting materials, forms, and references for additional resources. The Diabetes Prevention and Control Program, in collaboration with the Department of Public Instruction, is distributing the manual as well as conducting training sessions directed at school staff, on the effective use of the manual within the school environment. Copies of the manual are available from the Wisconsin Division of Public Health, Diabetes Prevention and Control Program website: **www.dhfs.state.wi.us/health/diabetes/index.htm**. //2004//

***/2005/*** *No significant changes.* ***//2005//***

**Folic Acid**

/2004/ During 2002, a folic acid education curriculum, Folic Acid: Getting the Word Out, was developed for use with family planning clinic staff members. The goal of this curriculum is to increase the knowledge of family planning clinic staff regarding the importance of presenting folic acid information to all clients of reproductive age. Participants in all five DPH regions were reached during this education initiative through face-to-face presentations and a statewide teleconference. A videotape of this training was also distributed to all family planning clinics for future training needs. Future plans for folic acid training include expanding this training initiative to include OB/GYN clinics and additional family planning clinics. //2004//

***/2005/*** *No significant changes.* ***//2005//***

**Youth Violence Prevention**

One organization with whom we have developed a strong working relationship over the past 12 years is the Black Health Coalition of Wisconsin. Coalition members include health care professionals as well as staff members from professional organizations such as the Black Nurses Association, the Wisconsin Association of Black Social Workers, and the Black Lawyers Association. Broad-based organizations such as the Milwaukee Urban League are also members of the Coalition.

During the MCH Block Grant funding cycle from 1994 through 1999, we awarded the Coalition a Title V grant to carry out a Family Resiliency Violence Prevention Program to study and apply through elementary school curricula, the resiliency of African American families as a protective factor against interpersonal youth violence. The program started with a study that identified resiliency factors among African American families in Milwaukee that protected youth from interpersonal violence. The study found that resilient families had higher levels of education, employment, male partner and other family support networks, and church attendance. They tended to be more mobile, as reflected by greater car ownership than the non-resilient families and an increased likelihood to have recently moved to a safer location within the city. Resilient families had a stronger sense of being able to succeed in managing their lives. The Black Health Coalition used the findings from its study to design a youth violence prevention curriculum for the Milwaukee Public Schools, which is currently in place. We used the findings to encourage other communities throughout Wisconsin to take a similar approach in tackling thorny MCH issues.

The Wisconsin Medical Society (WMS) is focusing on Youth Violence Prevention for 2002. Also, Wisconsin is fortunate in having a National Children's Center for Rural and Agricultural Health and Safety located in Marshfield and the Injury Research Center at the MCW in Milwaukee.

/2003/ An example of another effort that includes youth violence prevention is the SPI workgroup. Its overall mission is to raise public awareness and provide education. Membership of this workgroup includes Bureau and Division staff as well as other Divisions in the DHFS and community partners. Domestic violence and sexual assault are being addressed partnering with our Injury Prevention Section. BFCH staff are working with the Wisconsin Coalition Against Domestic Violence on their National Health Care Standards Campaign, funded through the Family Violence Prevention Fund. Activities include domestic violence and teens and domestic violence and public health, etc.

/2004/ The SPI Workgroup continues its mission. Membership includes representatives from HOPES, BFCH, BEMSIP, BMHSAS, DPI, FIC, NCCRHAS, MHA of Milwaukee, WUMH. Membership will be expanded to include NAMI, WMS, and others. The PHPS will develop evaluation tools and other outcome methods to measure the effectiveness of our efforts. Local collaborative efforts will be shared with others across Wisconsin, especially targeting communities with high rates of attempts and incidence of suicide.

BEMSIP receives ongoing funding for rape prevention and education. Residents will be educated on sexual assaults, its effects and prevention methods through targeted media campaigns, written and verbal media responses, educational seminars, training programs, resource availability and resource development. This multi-faceted approach will work to create social change through education and awareness activities. //2004//

***/2005/*** *In spite of interest and interviews conducted, Wisconsin was unsuccessful in attracting a Public Health Prevention Specialist (PHPS). We have reapplied. SPI continues its work through presentations/displays at conferences, partnering in the development of training modules and fact sheets, provision of QPR and other training, mini-grants for suicide prevention in schools, etc. The Mental Health Association of Milwaukee, one of SPI members, will take the lead in applying for Blue Cross/Blue Shield (BC/BS) funds to assist with our efforts.*

*In April 2004, a number of sites in Wisconsin participated in the national bullying prevention campaign teleconference/webcast. Discussion notes have been shared and an action plan will be developed. Project Ujima from Milwaukee was one of the host sites for the teleconference/webcast and continues its efforts toward prevention of youth violence.*

*The sexual assault prevention and awareness (REAL MEN RESPECT) campaign was launched in September 2003 to prevent sexual assault and promote healthy teen relationships.* ***//2005//***

**<u>African American Infant Mortality</u>**

An example of our efforts to become more community-based and resiliency-focused in our work with high need populations relates to the large disparity in infant mortality between black and white infants in Wisconsin. This example directly applies to our focus on addressing Outcome Measures #1-#5.

Infants born to African American women in Wisconsin are three times as likely to die in the first year of life as infants born to white mothers are. The Wisconsin African American infant mortality rate has averaged 18 deaths per 1,000 live births over the last decade. On the other hand, the ratio of American Indian infant mortality to the white rate has fallen from three to one in the mid 1980s to two to one in the late 1990s.

Previous research has attempted to explain disparities in health outcomes by focusing on traditional risk factors such as differences in socioeconomic status and higher levels of risk behavior among African American women. However, according to several studies in the United States, the gap between the two groups for low birth weight, a major contributing factor to infant mortality, persists regardless of socioeconomic status.

These disparities may be due, at least in part, to chronic stress that all African Americans experience as a result of discrimination. This stress may result in physiologic changes that place the individual at higher risk for a variety of illnesses and conditions, including low birth weight. Also, institutional discrimination may contribute to the barriers that African Americans encounter when gaining access to and effectively utilizing the health care system.

The Title V MCH/CSHCN Program, supported by the State Health Officer, convened a workgroup in 1995 to come up with a fresh approach to reducing African American infant mortality in the state. The group, chaired by the CMO for BFCH, includes members of the African American community (including faith-based organizations) as well as public health and medical professionals. The group has developed unique partnerships. Conversations and subsequent collaboration among people who would not necessarily otherwise work with each other occur through this group. For example, an academic family practice physician interacted in detail with the director of a community-based organization serving people of color in Milwaukee.

/2002/ After an extensive literature review, the group concluded that behavioral and other traditional risk factors account for only about two-thirds of the gap between white and black low birth weight and IMR. The group hypothesized that stress and racial discrimination may account for the remaining gap.

However, instead of studying the gap within a risk framework, the group decided to focus on the potential for resiliency factors to improve black infant survival. Funded in 2000 by the Wisconsin Council on Developmental Disabilities, the Black Health Coalition launched the initial pilot stage of a long-term study to determine the extent to which resiliency in African American women, families, and their communities improves infant survival and thriving. The pilot tested the value of a resiliency assessment tool for its applicability to African American pregnant women. The larger study, for which funding is now being sought, will address the ability of a woman and family to thrive in the midst of stress. It will take into account the capacity to deal with less studied risk factors such as the impact of stressful life events, racial discrimination, residential segregation, and gender roles on birth outcomes and infant health. The primary leadership for the study comes from the Black Health Coalition of Wisconsin, which, as mentioned above, has carried out research on African American family resiliency related to the prevention of interpersonal violence among youth in Milwaukee. The results of the infant mortality resiliency research will be used to develop resiliency-based policies, programs, and services that specifically address closing the gap between African American and white infant mortality in Wisconsin.

In our work with the African American, Latino, American Indian, Southeast Asian, and other communities of color, the Title V MCH/CSHCN Program in Wisconsin has gained valuable insight on the complexities and opportunities inherent in implementing the Five Guiding Principles. These communities have inspired us to examine the principles in greater depth and humility. Organizations such as GLITC and the Tribal Health Centers have practiced in an exemplary way the family-centered and community-driven strategies needed to eliminate unjust health

disparities due to deeply rooted systemic factors. By working with these communities, we acquire knowledge that we can apply to all children and families in the state.

These initiatives have inspired Title V to incorporate the vital importance of community driven coalitions into all MCH efforts in Wisconsin. In order to sustain the work of these efforts, we need a wide diversity of people - consumers, advocates, community residents, public health, HMOs, business, the media, policy makers - who are willing to take shared responsibility for and investment in this work.

Both Healthy Start Projects in Wisconsin, for example, have consortia that bring to the table numerous family members whose voices are consistently validated. We have been able to support these and other projects that make every effort to welcome and include family members in all phases of implementation. Title V in Wisconsin has greatly appreciated the leadership provided by these programs.

The capacity to sustain community-driven and family-centered MCH programs in the long term and in a systemic way is one of our greatest challenges over the next decade.

/2003/ In 1995, DPH formed an African American Infant Mortality Workgroup to develop community-based research and policies to reduce the gap between African American and White infant mortality. In 2000, the Black Health Coalition of Wisconsin, Inc. piloted a prenatal resiliency questionnaire to identify resiliency characteristics among African American pregnant women and their families who reside within areas of Milwaukee served by the MHBP. The Black Health Coalition is now planning a comprehensive study to identify resiliency-based solutions to the infant mortality disparity. //2003//

***/2005/*** *At the Healthy Babies in Wisconsin Summit, Michael Lu, MD, MS, MPH from UCLA introduced a life course perspective shedding light on racial and ethnic disparities in birth outcomes. Recent studies have focused on the processes through which economic circumstances, environmental issues, and social conditions create situations that expose African American women to stress and chronic strain, eventually leading to adverse pregnancy outcomes. Stress has been associated with preterm birth. Chronic stress has been shown to impair immunity which may provide one explanation why Black women who are pregnant are more prone to infections. Dr. Lu explained racial and ethnic disparities in birth outcomes as the consequences of disadvantages and inequities carried over a lifetime of differential exposures.*

*To address disparities we must look beyond the nine months of pregnancy. At a follow-up presentation at the Wisconsin Association for Perinatal Care Annual Meeting, Dr. Lu suggested the following strategies:*

1. *Increase access to interconception care*
2. *Increase access to preconception care*
3. *Improve the quality of prenatal care*
4. *Strengthen the capacity of male partners to stay involved*
5. *Enhance systems integration and service coordination for social support*
6. *Increase reproductive social capital in the communities*
7. *Invest in community building*
8. *Build community partnerships*
9. *Address issues that disproportunantly affect women of color through policy advocacy*

*10. Undo racism*

*The Milwaukee Healthy Beginnings Project with the Black Health Coalition plans to further explore the Life Course Perspective with Dr. Lu at a June 2004 meeting in Milwaukee with consortia members and key leaders.*

*At the Healthy Babies summit, the Perinatal Periods of Risk Model was presented as a way of looking at fetal and infant mortality data. The model considers birth weight and age at time of death to provide information that helps communities identify priority needs and interventions. Maternal Health/Prematurity is the greatest contributor to African American IMR. Women's preconceptional health and health during pregnancy are important to the health of her baby. Appropriate health and social services for women throughout their early and childbearing lifespan may help prevent infant deaths. Deaths of babies greater than 1,500 grams during the infant period from one month to one year of age is also high for African Americans. Possible prevention interventions include encouraging appropriate sleep positions and breastfeeding, injury prevention, smoking cessation programs, mental health care for parents, and immunization programs. // **2005**//*

**Milwaukee Healthy Beginnings Project**

/2004/ Since July 2001, the MHBP has expanded its service area from 8 to 12 zip codes and expanded the FIMR project to include the entire city of Milwaukee instead of just the Healthy Beginnings project area. They have advocated for Medicaid benefits for incarcerated women and established a Perinatal Health Program in the Milwaukee County Jail which includes screening, referral and treatment for depression, domestic violence, and AODA issues. They provided targeted case management services to uninsured incarcerated women and undocumented Latino women and maintained access to prenatal care for undocumented and at risk women by continuing to fund enhanced clinical services. Outcomes for 2002 (Number of infants=221) include: 7.2% of infants were low birth weight; 1.8% were very low birth weigh; and 11% of infants were born preterm. For pregnant participants (N=385) 74.5% received first trimester prenatal care; 64.9% of clients who speak English as a second language entered prenatal care in the first trimester; and 21.8% of women were able to stop/decrease their smoking after a health education intervention. //2004//

***/2005/*** *Milwaukee Healthy Beginnings Project promotes access to necessary perinatal services to all women, their infants and families in the City of Milwaukee. MHBP has mobilized a coalition of stakeholders who are committed to addressing some of the fundamental factors associated with high rates of infant mortality in the City of Milwaukee. MHBP plans to reduce the infant mortality by implementing the following project strategies: 1) Provide community-based prenatal care services which are culturally/linguistically competent through expanded outreach/ client enrollment recruitment and enhanced clinical services to pregnant women and their infants in the Project Area; 2) Continue the MHBP Consortium in Milwaukee in order to increase the communication between the communities of concern, serve providers, government agencies, and other stakeholders; 3) Continue and expand health educational services designed to increase healthy births and decrease teen pregnancies; and 4) Provide case management services to high-risk undocumented pregnant Latino women and to pregnant and postpartum women and make referrals for services.*

*MHBP contracts with a number of community agencies to provide services:*

- *Milwaukee Health Department coordinates the Fetal and Infant Mortality Review Program*

- *Healthcare for the Homeless provides outreach and case management services*
- *Asha Family Services provides outreach services, depression screening of incarcerated pregnant and postpartum women, AODA and mental health services*
- *Milwaukee Health Services provides case management services and interconceptional care*
- *St. Joseph's Medical Center provides case management services and interconceptional care*
- *Community-based providers are funded for enhanced clinical services*

*MHBP served 256 pregnant women in 2003, 141 infants less than 1 year old and 162 children ages 1-24. The program in the Milwaukee County Jail offered depression screening for 36 pregnant women, case management services for 120, AODA and mental health services for 91, and referral to PNCC services for 42 pregnant women released from jail. In 2004 services in the jail will be extended to postpartum women.*

*Outcomes in 2003 include the following: 3.0% (6/201) of infants among all live singleton births to programs participants had a very low birth weight; 6.0% (12/201) were low birth weight; 10.9% (22/201) were preterm; 82.4% (211/256) received first trimester care; 75.5% (40/53) of women with English as a second language entered prenatal care in the first trimester; 79% (109/138) of postpartum women received a completed referral; 1.5% (3/201) of infants were small for gestational age; 95.8% (340/355) of participants were screened for depression.* ***//2005//***

**Children with Special Health Care Needs**

During January 2000, the CSHCN Program developed and distributed a questionnaire to Wisconsin's 100 LPHDs to determine:

- the level of services and activities provided to children with special health care needs,
- the strengths and barriers to providing CSHCN services,
- training and education needs, and
- a CSHCN contact at each LPHD.

The questionnaire was constructed around the core public health functions: assessment, policy development, and assurance as they relate to the CSHCN population. The response rate, after reminders were sent, was nearly 100%. Results were summarized and presented at a Regional CSHCN Centers planning meeting. The information will assist the Regional CSHCN Centers in forming partnerships with their respective LPHDs as it relates to providing information and referral, service coordination, and parent support to children with special health care needs and their families.

LPHDs described several strengths in serving children with special health care needs. They mentioned:

- valuing children and families and providing family-centered care,
- being prevention focused,
- having experience with multiple agencies and skilled staff with a knowledge of local community resources, and
- experience providing services such as home visits and school health and other related services such as PNCC, Birth to 3, WIC, and immunizations.

When asked to identify their greatest barriers in serving this population LPHDs listed: limited funding, staff limitations, their own lack of awareness of the CSHCN population, and lack of communication from other CSHCN

providers after a referral was made by the LPHD. In addition, they cited an overall lack of CSHCN providers and family support groups available in the community.

Training and TA priorities were identified as the following: an orientation to the new five Regional CSHCN Centers; learn about more resources available in their region; receive general education about CSHCN health issues and new medical interventions; learn what other LPHDs are doing for this population; and gain a better understanding about data collection and evaluation. Specific TA requests pertained to: screening for children with special health care needs, health benefits counseling, targeted case management, service coordination, writing policies, preparing outreach education materials, integrating with Birth to 3, and school health services.

/2002/ Building upon the January 2000 survey results, the CSHCN Program conducted a telephone survey to better understand the needs of the LPHDs as they work with the Regional CSHCN Centers. In March 2001, all but ten of the health departments participated in a telephone survey exploring how the Regional CSHCN Centers are meeting needs and what can be strengthened as we progress through the next year. Some of the findings from this survey include:

- The Wisconsin CSHCN Program through the five Regional CSHCN Centers has an MOU with 77 of the 96 LPHDs (80%) to provide service coordination for children with special health care needs at the local level.
- Many LPHDs stated building more collaborations or strengthening existing collaborations with other community providers as they began to work with the Regional CSHCN Center and identify children in their community who have a special health care need. Of the community partners referred to, Birth to 3 Programs, Human Service Programs (such as Family Support), and School District Programs were cited most frequently.
- Overall, communication that occurred with the Regional CSHCN Centers was identified as useful, timely and responsive to the need. Many cited positive interactions with specific individuals. Most communication regarded requests for program related information as opposed to specific information for families.
- Very few LPHDs currently incorporate a parent perspective in any capacity in their health department. Only ten identified a way a parent is included in their activities. LPHDs stated incorporating a parent perspective in to program and policy planning, being a resource for other parents and knowing what is available in the community are useful roles the CPL will play in their health department.
- A variety of training and TA needs were identified by the LPHDs and shared with the Regional CSHCN Centers. Planning for future training events will be shaped by the input received from this survey.

/2003/ ETNs were done and focused on overviews of the Regional CSHCN Centers, service coordination, collaboration with the Wisconsin Birth to 3 Program and schools, and the role of the CPL. Part of the MOU between the Regional CSHCN Centers and the LPHD provided money for infrastructure building which was used by the LPHD to attend these trainings.

***/2005/*** *Building on the 46 LPHDs that provided results of the needs assessment conducted in their regions, the CSHCN program implemented objectives and action plans for year 2004 to satisfy unmet needs. The objectives could be individual household interventions or community based interventions or both. At the individual household interventions, LPHDs identified a minimum number of families for referral and follow-up and/or service coordination. Examples of the community systems interventions include:*

- *Education services to demonstrate an increase in knowledge related to Wisconsin Statewide Initiative on a medical home for CSHCN.*
- *Families that participate in Child Development Days in school districts will demonstrate an increase in knowledge related to CSHCN centers and services they provide.*
- *Ensure that 75% of high-risk newborns will receive, as part of newborn visitations program, information on health and dental screenings based on best practices recommendations.*
- *Collaboration: CSHCN LPHD staff will join forces with the family resource centers, prevention child abuse agencies, local school districts, health care providers and other community partners to plan a program to identify young children with diagnosed conditions, disabilities, and developmental delays.*
- *A CSHCN outreach plan will be developed.*

*These objectives were implemented into DPHs Grant and Contract (GAC) system of contracting with the Regional CSHCN Centers. The objectives entered into the GAC were to meet the requirements of the six core federal CSHCN Performance Outcomes. This system places a fiscal value to each objective and allows for more accountability - or measurement of the objectives in the contract.* ***//2005//***

**Evaluation Components of Children with Special Health Care Needs**

/2004/ The Wisconsin CSHCN Program is committed to evaluating the progress of the Regional CSHCN Centers and LPHDs toward the goal of forming a statewide, integrated system for children with special health care needs and their families by increasing the capacity of local communities to serve families. In this effort, different levels of evaluation are being implemented on a statewide basis. Each of the three components discussed below provides unique knowledge of the activities and results from both family and provider perspectives.

**Local Public Health Department's CSHCN Needs Assessment**

Local public health departments were offered financial support to conduct a needs assessment of the CSHCN population. The purpose of the needs assessment was to better understand the LPHDs role with and identify needs for children with special health care needs and their families while providing the LPHDs with information that will be useful to them in their assessment, policy development and assurance role. Two templates were provided to assist the LPHDs in identifying or further validating their role in the performance of community and individual level interventions for children with special health care needs. The reports were due by January 31, 2003 and subsequently reviewed during the months of February and March.

A total of 46 LPHDs completed a needs assessment. The information gathered will be useful to the LPHDs and the Regional CSHCN Centers. Many of the 46 LPHDs completing a needs assessment developed action steps based on the preliminary findings. The common themes that were reflected in each of the five regions validate the lack of dental care, respite care, recreational opportunities and child care for children with special health care needs across Wisconsin. There was also recognition of the important role LPHDs have or can have in their communities to address some of the needs for children with special health care needs.

**Information and Referral Satisfaction Survey**

Input from the families receiving services is an important aspect of the CSHCN Program evaluation. Families who receive information and referral services are asked to complete a satisfaction survey as well as providers who utilize

these services. The written survey is available in both English and Spanish and can be completed over the telephone if the family chooses. The survey responses are compiled monthly and are used to improve the quality of the information and referral services provided by the Regional CSHCN Centers. Most current results are discussed within NPM #2 as it relates to Family Satisfaction.

**LPHD / Delegate Agency Family Satisfaction Survey**

In addition, families who receive service coordination services from the LPHD or delegate agency are queried regarding their experiences and satisfaction with service coordination. Beginning in June 2002, families have had an opportunity to complete a thirteen-question survey in English or Spanish that is compiled by an outside evaluator. Again, this written survey can be completed over the telephone if the family chooses. Aggregated reports are regularly reviewed to improve the quality of service coordination services provided to families. Most current results are discussed within NPM #2 as it relates to Family Satisfaction.

ETN programs in the State have been renamed Wisline Teleconferences. Wislines topics focused on mental health for children with special health care needs, Supplemental Security Income, the medical and dental home concept, and transitions for children with special health care needs. LPHDs attend these training opportunities and provide evaluations of each program content, as do all other participants. Also the Birth to 3 Program hosted a Wisline on the relationship between the Birth to 3 Program and the Children with Special Health Care Needs Program attended by LPHDs. //2004//

**Evaluation components of Children with Special Health Care Needs**

***/2005/*** *The Wisconsin CSHCN Program is committed to evaluating the progress of the Regional CSHCN Centers and LPHDs toward the goal of forming a statewide, integrated system for children with special health care needs and their families by increasing the capacity of local communities to serve families. In this effort, different levels of evaluation are being implemented on a statewide basis. Each of the three components discussed below provides unique knowledge of the activities and results from both family and provider perspectives.*

*1) Information and Referral Satisfaction Survey*

*Input from families receiving services is an important aspect of the CSHCN Program evaluation. Families who received information and referral services were asked to complete a satisfaction survey as well as providers who utilize these services. The written survey was available in both English and Spanish and could be completed over the telephone if the family so chose. Monthly surveys were conducted through January 2004. The surveys had a great response rate and were very positive. Through January of 2004 there were 1,628 distributed with a 56.4% response rate. The survey responses were beneficial in improving the quality of the Information and Referral services provided by the Regional CSHCN Centers. It was decided that these surveys were no longer necessary on a monthly basis, so they will be sent out only during the months of April, July, and October in 2004.*

*2) LPHD/Delegate Agency Family Satisfaction Survey*

*In addition, families who receive Service Coordination services from the LPHD or delegate agency were queried regarding their experiences and satisfaction with service coordination. Beginning in June 2002, families had an opportunity to complete a thirteen-question survey in English or Spanish that was compiled by an outside evaluator.*

*Again, this written survey could be completed over the telephone if the family so chose. Aggregated reports were regularly reviewed to improve the quality of service coordination services provided to families. Although the distribution and/or response rate was low, the results received were very positive. Due to the low response rate, it was decided not to continue with this survey.*

*3) Retreats/Listening Sessions*

*Additional evaluations were made with various CSHCN staff to attend scheduled Retreats. The first Retreat included the Regional CSHCN staff and central CSHCN office staff. This was intended to gather input from the Regional CSHCN Centers and CSHCN central office to help determine goals accomplished and if there may be more efficient methods to reach our goals and objectives. The second Retreat included DPH Regional Office staff and CSHCN central office staff for the same purpose. A third Retreat was conducted that included a CSHCN central office staff, CPLs and parents. These were all helpful in determining what the program had accomplished and to ensure the program is heading in the right direction.* ***//2005//***